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ABSTRACT

The executive summary reports on a project to determine the prevalence of disability among American Indians, to identify special problems of American Indians related to vocational rehabilitation, and to survey the extent of cooperative efforts among programs conducted under the Rehabilitation Act of 1973. The summary contains the following components: (1) a description of the American Indian population, (2) a description of the cultural and social characteristics of American Indians that are contributing factors to their disability status and the delivery of rehabilitation services, (3) a summary and conclusions of the major findings of the study, (4) recommendations for improving the status of disabled American Indians, and (5) recommendations for future research. Among findings are the following: 9.88% of the American Indian school age population is handicapped; mortality data indicate a death rate of 1.5 or more times that of the general population and nearly double the general population death rate for ages 15 through 44; unemployment among American Indians is about five times higher than that of the total civilian labor force; and there is a high level of awareness on the part of the vocational rehabilitation state administrators regarding legislative changes to improve services to disabled American Indians. (DB)

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A STUDY OF THE SPECIAL PROBLEMS AND NEEDS OF AMERICAN INDIANS WITH HANDICAPS BOTH ON AND OFF THE RESERVATION

VOLUME I

Executive Summary

Prepared for

U. S. Department of Education
Office of Special Education and Rehabilitative Services
Rehabilitation Services Administration

September 14, 1987

Prepared by

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The Study of the Special Problems and Needs of American Indians with Handicaps Both On and Off the Reservation consists of three volumes. Volume I provides an Executive Summary of the study findings, recommendations and conclusions, and future research needs. Volume II consists of five individual study reports, representing the data, analysis, and summary of the studies. Volume III provides appendices to the individual study reports.

This study was completed in part with funds from U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research in Cooperative Agreements #G0083C0094, and #G0083C0095.

A STUDY OF THE SPECIAL PROBLEMS AND NEEDS OF AMERICAN INDIANS WITH HANDICAPS BOTH ON AND OFF THE RESERVATION

Introduction

The Rehabilitation Act of 1973, as amended by Public Law 99-506, establishes the development and implementation, through research, training, services, and the guarantee of equal opportunity, of comprehensive and coordinated programs of vocational rehabilitation and independent living, for individuals with handicaps in order to maximize their employability, independence, and integration into the workplace and the community. Part D, Section 132, of the Act establishes that "a study of the special problems and needs of the Indians with handicaps both on and off the reservation" be conducted. In addition, "the study shall also evaluate the nature and extent of cooperative efforts among programs conducted under this Act."

This study was undertaken to respond to this legislative mandate by addressing three major questions:

- What is the prevalence of disability among American Indians?
- What are the special problems of American Indians related to vocational rehabilitation?
- What is the nature and extent of cooperative efforts among programs conducted under this Act?

A process for responding to the legislation was established by the Rehabilitation Services Administration (RSA). First, an Advisory Committee on Implementing the New Rehabilitation Act Legislation for Handicapped American Indians and Native Americans was established. The Committee consisted of representatives from the Office of Special Education and Rehabilitative Services, the Director of the National Institute on Disability and Rehabilitation Research, the Assistant Secretary of the Interior for Indian Affairs, the Director of Indian Health Services, representatives of affected Indian tribes and tribal groups, and other appropriate officials, organizations, and individuals.

The Advisory Committee participated in the establishment of the study questions and scope. Three meetings were conducted in Washington, D.C., by the Rehabilitation Services Administration (RSA) to obtain input and feedback regarding the study implementation and findings.

The study questions were addressed in the following manner:

1. The first question was addressed by obtaining information on the number of American Indians who are disabled currently being served in the educational and health care service delivery systems. Data on elementary and secondary school-age children with handicapping conditions was secured from the U.S. Department of Education, Office of Civil Rights. In addition, the U.S. Department of Interior, Bureau of Indian Affairs (BIA), provided data on children with handicapping conditions attending the BIA schools. These two sources of information constituted the data for an analysis that was conducted on the prevalence of handicapping conditions identified within the educational system.

National data from the U.S. Department of Health and Human Services, Indian Health Service (IHS), was secured in order to assess the incidence of disease conditions as served by the IHS health care system for American Indians. This analysis consisted of identifying the major disease categories contributing to the poor health status of American Indians and was used to project their rehabilitation needs.

The educational and health-related data analysis provide an assessment of the treated prevalence of disability among American Indians.

2. The second question, related to identifying the special vocational rehabilitation needs of American Indians, was addressed through an analysis of the labor market with implications for vocational programming with American Indians. This analysis consisted of the use of several major data bases that allowed an analysis of the unemployment status of American Indians, their occupational patterns, the type of industries they are employed in, work disability status, and occupational placements of successfully rehabilitated American Indians in the State-Federal rehabilitation system.

Four major data bases were used. The sources for this data included: (a) the U. S. Department of Interior, Bureau of Indian Affairs; (b) the U.S. Department of Labor, Bureau of Labor Statistics; (c) the U.S. Department of Commerce, Bureau of the Census; and (d) U.S. Department of Education, Rehabilitation Services Administration.

3. The third question, related to the nature and extent of cooperative efforts among programs conducted under the Rehabilitation Act, was addressed by conducting telephone interviews with three respondent groups: (a) State Vocational Rehabilitation (VR) and Blind Service administrators; (b) State VR district managers; and (3) Indian VR project directors. The interviews consisted of questions related to several key issues that would identify the special problems and needs of American Indians with disabilities, as well as articulate the nature and extent of cooperative efforts between State VR agencies and Indian tribal groups.

Specifically the following issues were addressed: (a) the policies, strategies, and activities of the State VR agencies that have been implemented, or are being planned for implementation, regarding the delivery of vocational rehabilitation services to American Indians; (b) the problems, or barriers, related to improving vocational rehabilitation services to American Indians who are disabled; (c) the solutions to overcoming the barriers to improving vocational rehabilitation services to American Indians; and (d) the State VR agencies' response to Part D, Section 101 (20), requiring that the State actively consult with Indian tribes, tribal organizations, and Native Hawaiian organizations in the development of the State Plan.

The executive summary consists of the following: (a) a description of the American Indian population; (b) a description of cultural and social characteristics of American Indians that are contributing factors to their disability status and the delivery of rehabilitation services to them; (c) a summary and conclusions of the major findings of the study; (d) recommendations for improving the status of American Indians with disabilities based upon the study conclusions; and (e) recommendations for future research.

Characteristics of the American Indian Population Contributing to Their Disability Status

The population characteristics of the American Indian people distinguish them from the general population at large. The 1980 U.S. Census (U.S. Bureau of the Census, 1983) reported 1.4 million American Indians in the United States. The American Indian population has nearly tripled in the twenty year period from 1960 to 1980 (U.S. Congress, Office of Technology Assessment, 1986). A high birth rate among American Indians contributes to this increase. When compared to White, Black, and Hispanic groups, American Indians have the highest birth rate. This is, in part, explained by the larger proportion of the American Indian population that is of childbearing age.

The majority of the American Indian population live west of the Mississippi River, where four states alone account for over 40% of the population (listed in the order of the largest state population): California, Oklahoma, Arizona, and New Mexico (Stock, 1987). Approximately 46% (644,000) of the American Indian population reside on identified Indian areas or in nonmetropolitan areas. Identified Indian areas are reservations, tribal trust lands, Alaska Native villages and historic areas of Oklahoma that consist of former reservations (U.S. Congress, Office of Technology Assessment, 1986). There are 309 federally recognized tribes and 197 tribal villages in Alaska (Federal Register, 1986). According to the 1980 U.S. Census, half (49%) of all reservation residents live on 10 reservations: Navajo (Arizona), Pine Ridge (South Dakota), Gila River (Arizona), Tohono O'Odham (Arizona), Fort Apache (Arizona), Hopi (Arizona), Zuni (New Mexico), San Carlos (Arizona), Rosebud Sioux (South Dakota), and Blackfeet (Montana).

Approximately 54% of the Indian population now live in central cities or urban areas outside of central cities. Ten metropolitan areas with the highest urban population of American Indians are: Los Angeles-Long Beach, Tulsa, Oklahoma City, Phoenix, Albuquerque, San Francisco-Oakland, Riverside-San Bernardino-Ontario, Seattle-Everett, Minneapolis-St. Paul, and Tucson.

The geographic distribution and residency patterns of American Indians are different from that of the general population, as well as any other minority group. Whereas the highest percentages of minorities in general are city dwellers, with high concentrations living in the inner cities, almost half of the American Indian population live in rural areas. Problems in providing human services to rural residents is well documented and results in poor access to services, limited resources, transportation problems, and underutilization of existing services. These factors contribute to higher rehabilitation costs.

The American Indian age distribution also differs sharply from that of the total U.S. population (Stock, 1987). In 1980, almost half (43.8%) of Native Americans were under 20 years of age, and only 5% were 65 years or older; compared to 32% under 20 years and almost 12% over 65 years of age in the U.S. total population. The median age of American Indians in 1980 was 24.4 years, about 7 years younger than that of the general population.

A description of the American Indian population is influenced by the definition of tribal membership. Tribal membership criteria varies from tribe to tribe, as well as across data sources. Although approximately 25% of tribes now require a blood quantum level of one-fourth, tribal membership criteria varies from proof of descendancy to one-half blood quantum. Eligibility for enrollment in a BIA funded school requires that a student be an enrolled member of a federally recognized tribe, or that the total blood quantum be one-fourth or more. The Indian Health Service is not explicitly limited to members of federally

recognized tribes due to the variation across tribes in tribal membership requirements (U.S. Congress, Office of Technology Assessment, 1986). On the other hand, data from the U.S. Bureau of the Census is based on self-identification through self report.

Socioeconomic and Cultural Characteristics of American Indians

The socioeconomic and cultural characteristics of the American Indian suggest several factors that have been shown to be consistently related to minority health status (U.S. Department of Health and Human Services, 1985), and contribute to a unique profile with significant implications for rehabilitation efforts. Four factors discussed here are: (a) educational status; (b) economic status; (c) occupation and labor market participation; and (d) cultural differences.

Educational status. The overall educational attainment of American Indians is the lowest of all minority groups (U.S. Bureau of the Census, 1983). The 1980 U.S. Census reported that 56% of American Indians over the age of 25 have graduated from high school, compared with 69% of Whites. Among the 16 and 17 year old student population, significantly fewer American Indians are enrolled in high school. Only 76.6% of American Indians were enrolled in high school within this age range, as compared to 89% of Whites, and 87.9% of the Black student population.

Economic status. The poverty rate among American Indians is substantially higher than for the general population. In 1980, (U.S. Bureau of the Census, 1983) 27.5% of American Indians had incomes below the poverty level compared with 12.4% of the general population. The median family income in 1979 for American Indians was $13,678, compared to $19,917 for families of all races. Nearly half of on-reservation American Indian families with children lived on below-poverty or near-poverty incomes in 1979, and more than one-third of near-reservation families were in this category (U.S. Department of Health and Human Services, 1980). Twenty-three percent of the Indian households were headed by women, compared with 14% of the households of the general population. The average on-reservation American Indian family is larger (4.5 persons) than the average U.S. family of all races (3.3 persons).

Occupation and labor market participation. Occupation has typically been used as one of the indices of social status and helps to further describe the socioeconomic influences contributing to the disability status of American Indians. Unemployment among American Indians has historically been high. According to the 1980 U.S. Census, the unemployment rate for American Indians 16 years and older was twice that of the average of all races at 13.2%. The Bureau of Indian Affairs reported an unemployment rate of 38% during 1986 for the Indian population living on or near reservations. For the 28 states with 90% of the total American Indian population, the unemployment rate is 5.47 times higher on or adjacent to reservations than that experienced by the total civilian labor force in these states. Unemployment among American Indians reporting a work-related disability during the 1980 U.S. Census represents an equally alarming disparity, with 1.5 times as many American Indians reporting a work-related disability when compared to the general U.S. population. Although there is some variance in the unemployment patterns of American Indians from state to state, it is consistently higher than the total civilian unemployment rate.

Because of the limited number of jobs and the types of jobs available, particularly on reservations, participation rates in various occupations is affected. American Indians participate in managerial/professional speciality and technical/sales/administrative support occupations at lower rates when compared to the total civilian labor force. They participate in service and operator/fabricators/laborer occupations at higher rates.

Cultural differences. The mores and cultural patterns of the dominant society imposed upon American Indians have disrupted their traditional way of life (U.S. Department of Health & Human Services, 1985). "A sense of powerlessness and hopelessness has often been observed as a result and may be related to the high incidence of alcohol abuse, suicide, depression, and obesity among this population" (p. 59). Alcoholism is sometimes viewed as a way of coping with cultural disruption, and alcoholism alone has significantly contributed to a higher death rate at most age levels for American Indians when compared to the total U.S. population.

Traditional values, beliefs, and customs, however, have been largely maintained by American Indians, providing a source of strength to cope with stressors. Traditional strengths include the family, the tribe, religious beliefs, and the land itself. Traditional medicine men and women still play significant roles in the health and healing practices of this population. The continued influence of the dominant society on the American Indian people results in cultural change and disruption within the American Indian culture. Traditional beliefs and culturally specific family patterns may affect their ability to withstand social, economic, and psychological stressors (U.S. Department of Health & Human Services, 1985).

An important element of the American Indian culture is their language. There are still over 250 native languages in the U.S. today (Chafe, 1974). Language differences from the dominant society can greatly influence the diagnostic and eligibility process of rehabilitation, as well as create barriers to successful rehabilitation service delivery. Complicating the language differences today is the large number of bilingual native speakers, many of whom may experience limited English proficiency.

Summary. The population, socioeconomic and cultural characteristics of the American Indian people distinguish them from other minority groups and from the dominant society. These factors contribute to their disability status and influence rehabilitation efforts with them. The American Indian with disabilities is much more likely than an individual from the general population to be a rural, reservation resident, representing residency patterns in geographic locations with sparse resources, significant distances to travel resulting in transportation barriers, and underutilization of existing resources because of isolation and lack of knowledge regarding the rehabilitation process. A study by O'Connell and Minkler (1987) documents some of the geographic isolation issues for Navajo vocational rehabilitation clients. Seventy-one percent of a sample of Navajo clients reported not owning a telephone. The average distance to the VR agency offices was 33 miles, with a range of 0-150 miles. These and other related variables were found to significantly influence the successful rehabilitation of the Navajo clients in the study sample.

The American Indian person with disabilities is also much less likely to have a high school degree. In a study by Martin and Luebbe (1987), the average reading level of a sample of American Indian vocational rehabilitation clients was below sixth grade.

American Indians are more likely to be on public assistance at the time of application for rehabilitation services, and much less likely to have a work history prior to rehabilitation. A study by Morgan and O'Connell (1987) documents the lower economic status of American Indian vocational rehabilitation clients served by the State-Federal rehabilitation system between 1980-82.

These geographic, educational, economic, and occupational/employment characteristics must additionally be considered within the context of the American Indian culture. Traditional values, beliefs, and customs continue to influence many American Indian people and have implications for improving vocational rehabilitation services to them. In addition, language differences must be considered as influential factors in successful service delivery . Martin and Leubbe (1987) reported that language differences can interfere with accurate assessments of the abilities of American Indians in the rehabilitation process. In a sample of primarily Navajo VR clients they found that the tested reading levels in English were discrepant from both attained educational levels and performance and nonlanguage measures of general abilities.

The information generated by the studies conducted for this report contribute additional information about American Indians in general, as well as those Indians who are disabled. The special problems and needs of Indians with handicaps are complex. The interaction of residency patterns, socioeconomic characteristics, and cultural factors with the nature and type of disabling conditions exhibited by the population influence their disability status. Effective rehabilitation service delivery systems for American Indian people who are disabled must recognize these differences and identify strategies for improving services to this population.

Summary and Conclusions of Study Findings

The findings of the study will be summarized for each major section of the report. The four sections to be summarized are:

1. An analysis of the prevalence of disability among American Indians utilizing school-based data.

2. An analysis of the incidence of disability among American Indians utilizing health-related data.

3. An analysis of the labor market participation of American Indians with implications for rehabilitation.

4. The nature and extent of cooperative efforts by state vocational rehabilitation programs for Indian people who are disabled.

An Analysis of the Prevalence of Disability Among American Indians: School-Based Data

An analysis of elementary and secondary school data from the U.S. Department of Education, Office of Civil Rights and the U.S. Department of Interior, Bureau of Indian Affairs, was conducted in order to determine the prevalence of handicapping conditions among American Indian school-age children and compare it to other ethnic groups. It was anticipated that information on the prevalence of different handicapping conditions among the school age population would provide projections of the future rehabilitation needs of adults from this minority population.

The following results were identified:

- American Indians had the second highest percentage of students with handicapping conditions among minority groups in public schools; 9.88% of the American Indian school age population were identified as handicapped. Blacks had the highest percentage of school age students with handicapping conditions (10.31%).

- Learning disabilities was the largest category of handicapping conditions for American Indian public school children (5.28%); which is consistent with that for all other minority groups and Whites.

- However, a larger percentage of American Indian children were classified as learning disabled than for any other group (American Indian = 5.28%; Blacks = 4.26%; Hispanic = 4.14%; Whites = 4.14%; Asian = 1.66%).

- A larger percentage of American Indian children were also found in the speech impairment and multi-handicapped categories than the respective percentages for the U.S. population.

- A lower percentage of American Indian children were identified as mentally retarded than that for the U.S. population.

- American Indian children were also less likely than the U.S. population to be identified in the following handicapping categories: seriously emotionally disturbed, hearing impaired, visually impaired, orthopedically impaired, and other health impaired conditions.

- A total number of 44,752 American Indian children were projected to have a handicapping condition.

- Fifteen states accounted for nearly 90% of all projected American Indians with handicapping conditions in the country. By rank order according to the greatest number of American Indian students with handicapping conditions, the 15 states are: Oklahoma, Arizona, North Carolina, Montana, Alaska, New Mexico, Minnesota, California, Washington, North Dakota, South Dakota, Michigan, Oregon, Wisconsin, and Utah.

- Prevalence rates varied greatly from state to state, resulting in very different patterns of handicapping conditions across the U.S. for American Indians.

- Twenty-three states had a larger percentage of identified students with handicapping conditions who are American Indian than their respective percentages of total enrollment for American Indians.

An Analysis of the Incidence of Disability Among American Indians: Health-related Data

An analysis of disease conditions among hospitalized American Indians served by the Indian Health Service was conducted in order to determine the incidence of health-related problems within this population. Data from the U.S. Bureau of Health Statistics was also analyzed to provide a comparison of disease conditions between American Indians and the general population. It was anticipated that information on the disease conditions of American Indians would provide projections of the rehabilitation needs of American Indians who are disabled.

The following results were identified:

- IHS mortality data indicated that the death rate among American Indians was 1.5 or more times the All Race death rates for most age categories up to age 55 years, and nearly double the All Races death rate for ages 15 through 44 years. American Indians are much more likely to die at an early age than the general U.S. population.

- Deaths due to alcoholism, accidents, suicides, and homicides were disproportionately represented among American Indians. Between the ages of 15 through 34 years, American Indians were over 11 times more likely to die due to alcoholism when compared to the death rate for All Races. Between the ages of 25 through 64 years American Indians were 3 times more likely to die due to accidents.

- The high incidence of deaths due to suicides and homicides among American Indians suggested a high incidence of psychological disorders.

- Deaths due to pneumonia and influenza, diabetes mellitus, and tuberculosis were also disproportionately high among American Indians when compared to that for All Races.

- The rate of diagnosed disease based upon hospitalization data was considerably lower for American Indians in IHS service areas than for the U.S. population as a whole. Given the high death rates of American Indians at early ages and other evidence of American Indian health problems, this lower rate may indicate that American Indians generally have less access to inpatient medical services.

- Sensory impairments, identified as eye and ear conditions, are disproportionately high among American Indians when compared to the U.S. All Races. Congenital conditions of the eye for American Indians were 1.26 times that of the U.S. All Races rate, while American Indians were 2.89 times more likely to be hospitalized for conditions of the ear. Otitis media hospitalization rates were 4.02 times greater than that for the U.S. All Races rate.

- U.S. Census data indicated that American Indians were 1.5 times more likely to report work-related disability than individuals from the general population.

- American Indians exhibited health-related problems at earlier ages than individuals from the general U.S. population, with the highest relative rates reported for the age group 15 through 35 years.

- The health problems of American Indians varied greatly across regions of the country and even within regions, resulting in very different patterns of disability across the U.S. for American Indians.

- The rate at which the State-Federal rehabilitation system provided rehabilitation services to American Indians who are disabled was substantially lower than for the U.S. population as a whole.

- RSA data showed that American Indians who are disabled appeared to be underrepresented in the State-Federal rehabilitation system (when compared to conditions identified in the hospitalization data) in the area of sensory disorders (conditions of the eye and ear), orthopedic impairments due to accidents, asthma and allergies, diabetes, speech conditions, and skin conditions.

An Analysis of the Labor Market Participation of
American Indians with Implications for Rehabilitation

An analysis of three major data sources related to the unemployment rates of American Indians was conducted. Data from the U.S. Department of Interior, Bureau of Indian Affairs (BIA), U.S. Department of Labor, Bureau of Labor Statistics (BLS), and U.S. Department of Commerce, Bureau of the Census was used for this analysis to compare the unemployment rates, as well as occupational patterns and type of industries employed in, between American Indians and the total civilian labor force. Data from the U.S. Bureau of the Census was also used to compare the work disability status of American Indians and the total population. Data from the U.S. Department of Education, Rehabilitation Services Administration was used to compare the occupational placements of successfully rehabilitated American Indians in the Rehabilitation Services Administration system with that of the general population.

The following results were identified:

- Unemployment among American Indians was reported to be 5.47 times higher (BIA and BLS estimates for 1986) or 4.49 times higher (1980 U.S. Census data) than the unemployment for the total civilian labor force.

- The unemployment rates for American Indians living on or adjacent to reservations were 1.97 times higher than for the total American Indian population (living both on and off reservations).

- For the total American Indian population living both on and off reservations, a 2.28 times higher rate of unemployment was reported than for those from the total civilian labor force.

- Unemployment rates for American Indians across geographic regions was consistently higher than for the total civilian labor force.

- American Indian males and females participated at different rates in several major occupational groupings when compared to the total civilian labor force. American Indian males and females were less frequently employed in managerial/professional specialty and technical/sales/administrative support occupations when compared to the total civilian labor force.

- The total male civilian labor force had a 1.45 times higher rate in executive/administrative, a 1.55 times higher rate in professional specialty and a 2 times higher rate in sales occupations when compared to American Indian males in the labor force.

- American Indian males and females had higher rates of participation in service and operator/fabricator/laborer occupations.

- American Indians showed different patterns of employment by industry when compared to the total civilian labor force. Total employed persons showed a 2 times higher rate in the manufacturing industry, 3.5 times higher rate in transportation/communication/public utilities, 2.3 times higher rate in wholesale trade, 3.4 times higher rate in retail trade and a 3 times higher rate in finance/insurance/real estate industries when compared to American Indians employed on reservations.

- The American Indian employment by industry patterns were fairly consistent across regions of the U.S.

- For the 28 targeted states under analysis, the work disability rate for American Indian males was 1.4 times higher and for American Indian females was 1.6 times higher than for the total population by gender.

- American Indian clients in the State-Federal rehabilitation system were placed into occupational categories at somewhat consistent rates when compared to the total caseload of VR clients.

The Nature and Extent of Cooperative Efforts by State Vocational Rehabilitation Programs for Indian People Who Are Disabled

An analysis of the policies, strategies, and activities of the State VR agencies for addressing issues related to the improvement of rehabilitation services to American Indians, as identified by the Rehabilitation Act of 1973, as amended by Public Law 99-506, was conducted. Telephone surveys were conducted with three respondent groups: (a) State VR and Blind Services administrators; (b) VR district managers; and (3) Indian VR project directors. Responses to the survey provided information relevant to the implementation of the Act.

The following results were identified:

- There was a reported high level of awareness on the part of VR State administrators regarding the legislative changes targeting improved and increased VR services to American Indians with disabilities.

- Most State VR agencies are conducting planning activities in response to the 1986 Rehabilitation Act amendments. Ten states have established or plan to establish cooperative agreements between the State VR and tribal entities.

- Variability across State VR agencies in response to implementation of the 1986 Rehabilitation Act amendments was evident, and was influenced by such factors as the total Indian population residing in the State, the number of recognized tribes within the State, residency patterns of Indian populations (urban vs rural reservation), experience with previous efforts to serve reservations, and efforts by other advocacy groups.

- State VR respondents rated the priority of improving VR services to American Indians as high (16%), medium (42%), and low (42%).

- Half of the respondents reported that their agency had not made plans to meet independently with either individual tribes or inter-tribal councils for consultation in development of the State VR Plan, but had invited Indian tribes to testify at public hearings held throughout the State. Respondents indicated, however, that participation in these forums had been poor.

- State responses varied in their identification of State-level versus field-level responsibility for initiating consultation with Tribes, as required by the 1986 Rehabilitation Act amendments.

- The following barriers to VR service delivery to American Indians were consistently identified:

    - a lack of employment opportunities for VR clients on or near the reservation;

- cultural differences, which affect the VR ability to appropriately serve Indian clients and the ability of Indians to fit into the traditional VR service delivery patterns;
- isolated geographic location of reservation-based Indians and associated problems with transportation for accessing services;
- lack of interagency cooperation, in both identifying and serving VR clients;
- itinerant service delivery strategy;
- high level of substance abuse, resulting in a more difficult disability condition to rehabilitate.

- Half the respondents reported that a staff responsibility for coordination, planning and implementation of efforts in response to the amendments had been designated.
- One-fourth of the State VR respondents indicated that central staff responsibility was not necessary for implementation, but that increased field staff responsibilities would be necessary.
- Development of employment opportunities on or near the reservation was cited by respondents from all three groups to be central and necessary to improving and increasing VR services to American Indians with disabilities living on or adjacent to reservations.
- District VR managers reported that the cost of rehabilitation of American Indians who are disabled is less than that for the general population because of similar benefits provided by other service agencies serving American Indians.
- District VR managers reported that on-site VR services, delivered to reservations, were most effective in developing VR services with Indian people, and that the identification of a liaison or resource person from the reservation who facilitates the development of services between the tribe and the VR agency is important.
- Indian VR project directors reported varying degrees of communication and cooperation with the respective State VR agencies. All reported that continuing efforts to define the State VR-tribe relationship was important.
- Staff development and in-service training were cited by the Indian VR project directors as important priorities and essential to providing services comparable to the State VR agency.

RECOMMENDATIONS FOR IMPROVING THE STATUS OF AMERICAN INDIANS WITH DISABILITIES

Introduction

Several major national databases have been analyzed and provide information regarding the socioeconomic, cultural, employment, and disability status of American Indians. The factors contributing to the special problems and needs of American Indians who are disabled both on and off the reservation defy simplistic solutions. This section will summarize key recommendations for improving the rehabilitation services to American Indians based upon the study findings.

Socioeconomic and Cultural Issues

It is evident that the socioeconomic characteristics of and the cultural influences on the American Indian population are unique and distinguish them from other minority populations and from the dominant society. The social status indices of education, income, and occupation suggest a population of people whose primary concerns are related to basic subsistence living issues. The interactions of these characteristics will vary from individual to individual and result in differential effects as it relates to their rehabilitation problems.

However, in general, dependency upon economic subsidies and a lack of employment history with limited exposure to the world of work, results in limited advantage to the primary gains of employment. Extended family influences are great within the culture, and the necessity of relocation for job training and employment may not positively balance out the loss of family contact and subsistence incomes. Lower educational levels and language differences create barriers to employment which may result in not only the need to relocate, but extended time for training in order to become competitive in the labor market. The geographic and socioeconomic characteristics of the American Indian population contribute to increased difficulties in accessing available services, with transportation a major barrier resulting in underutilization of services. Recommendations for improving the employment of American Indians with disabilities as it relates to their socioeconomic status will be provided in a subsequent section. Recognizing the cultural differences, the following recommendations are made for improving rehabilitation services to American Indians who are disabled.

RECOMMENDATION 1: ADDRESS THE CULTURAL INFLUENCES ON REHABILITATION SERVICE DELIVERY

- Rehabilitation policy-makers and service providers should acknowledge the unique significant influence of the characteristics of the American Indian culture on their participation in the rehabilitation process and develop an understanding of its influence on the delivery of rehabilitation services. Because of the diversity across tribal groups and their members in the specific values, beliefs, and customs of the cultures, as well as the degree of acculturation and use of native languages, information specific to the tribal groups and individuals being served should be developed and considered in implementing rehabilitation services.

- Vocational rehabilitation goals within the context of the American Indian culture should be reassessed. The rehabilitation of American Indians should take full advantage of rehabilitation outcomes that include, but are not limited to, competitive employment, in order to incorporate consideration of the socioeconomic, employment, and cultural factors of the American Indian people.

- Rehabilitation services to American Indian people with disabilities should consist of strategies that incorporate the individual's immediate and extended family into the rehabilitation process.

- Public information programs informing Indian people about rehabilitation and disabilities should be initiated. An effort should be made to increase the Indian people's knowledge of the effectiveness of rehabilitation for improving the lives of Indian people who are disabled.

- Local, indigenous people should be utilized in the delivery of rehabilitation services to the extent possible, e.g. interpreters, transportation providers, interviewers, counselors.

- The State-Federal rehabilitation system should support the training of VR personnel on issues related to serving American Indians.

Population Characteristics

The American Indian population as a whole is much younger than the general population. They are also much more likely to be hospitalized at a younger age, even after accounting for the disproportionate number of American Indians in the younger age ranges. With a median age of 24.4 years (7 years younger than the general population), many American Indians are at the entry level in the labor market. However, high unemployment rates and limited occupational opportunities result in limited or no work histories and a general lack of exposure and understanding of the employment options in the total labor market. At the same time, the largest percentage of school-age American Indian children with handicapping conditions are learning disabled, suggesting that their success within the rehabilitation system could be quite high. Therefore, acknowledging the age characteristics of the American Indian population and their high risk for hospitalization and onset of disability at an early age, the following recommendation is made.

RECOMMENDATION 2: REHABILITATION SERVICES TO YOUNG AMERICAN INDIANS WHO ARE DISABLED

- In order to facilitate the successful transitioning of Indian youth into the rehabilitation system and the world of work, increased efforts should be made by the State-Federal rehabilitation system to coordinate with public and BIA schools serving American Indian children with handicapping conditions and with Departments of Labor.

Geographic Variance in the Distribution of the Prevalence of Disability

The school-based and health-related data indicate the degree of variability in the distribution of the prevalence of disability from tribe to tribe, state to state, and region to region. For example, in Minnesota, 42.17% of the American Indian student population enrolled in BIA schools were identified as handicapped, while California had only 3.55% of BIA enrolled students identified. The prevalence of handicapping conditions by handicapping category between states also varies. While Arizona identified only .71% of the American Indian school-age population attending BIA schools as mentally retarded, Oklahoma reported 2.04% for the same handicapping condition.

Similarly, diabetes, as an example of a health-related disability condition, makes up more than 6 percent of all diagnoses in four IHS areas (Nashville, Tucson, Bemidji, and Phoenix), a rate which is more than double that of the general population. However,

diabetes makes up less than one percent of the IHS caseload in the Alaska area. Even more striking is the variance within a region. While Tucson and Phoenix areas have over six percent of their caseload composed of diabetes, the Navajo area, situated geographically adjacent to the Phoenix area, has less than three percent of its hospital diagnoses in the diabetes category.

These specific examples characterize many such findings reported by the individual study reports. Therefore, recognizing the extensive degree of variability across geographic regions of the distribution of disabling conditions, the following recommendation is made.

RECOMMENDATION 3: ADDRESS THE VARIABILITY IN THE DISTRIBUTION OF DISABLING CONDITIONS

- Rehabilitation policy-makers and service providers should conduct outreach efforts as well as develop an increased capacity to serve those disability groups representing conditions of high prevalence within the American Indian population by the geographic location served.

VR-Tribal Relationships

The survey information from State VR administrators and district-level VR managers supports the need for positive VR-tribal relationships in the development and implementation of rehabilitation programs within Indian communities. The responses from 3 Indian VR project directors also strongly suggests that the future development of rehabilitation programs by Indian tribal organizations must be conducted within a cooperative framework between Indian tribes and the VR agency. Of the 28 states with significant populations of American Indians surveyed, all but one State VR administrator acknowledged awareness of the rehabilitation legislation related to improving VR services to American Indians. Variation occurred, however, across states in response to the legislation, with differing policies, strategies, and activities identified for addressing the Indian issue. The following recommendation related to a positive VR-tribal relationship for improving rehabilitation services to American Indian people who are disabled represents a summary of information provided by the survey conducted as a part of this report.

RECOMMENDATION 4: FACILITATE VR-TRIBAL RELATIONSHIPS TO IMPROVE VR SERVICE DELIVERY TO INDIAN PEOPLE

- Long-range State VR policies should be established for improving rehabilitation services to American Indian people who are disabled in order to reflect the importance of such an initiative. State-level policies should support the importance of the district-level administrator in directing regional efforts to improve rehabilitation services to American Indian people, as well as support the implementation of State policies by the local rehabilitation counselor.

- Short-term State VR policies should be established that acknowledge the extensive and often time-consuming effort that must be undertaken by rehabilitation counselors and other key rehabilitation personnel in creating a positive environment for cooperation with Indian tribal organizations. The development of human service programs on reservations and within Indian communities requires the development of trust and consistency on the the part of the service providers in order to insure cooperation with the tribal policy-makers and consumers. Rehabilitation counselors should be encouraged by State VR administrators to conduct program development activities on

reservations and in Indian communities that establish long-term relationships, but that may not result in traditional competitive employment closures in the short-term.

- State VR agencies should identify a liaison person from within the tribal community who can help facilitate the development and support of improved rehabilitation services. This individual could be a representative of the tribal council, a health professional from IHS or the tribal health division, mental health worker in the Indian community, or other appropriately identified individual who has worked effectively in the past within the community.

- The successful implementation of State VR agency policies and plans related to American Indians may be facilitated by designating an individual at the local, regional, or state level to have staff responsibility to coordinate planning and implementation of efforts in response to the Rehabilitation Act as it relates to American Indians with disabilities.

Interagency Cooperative Efforts

Many of the health-related conditions of the American Indian people contributing to their disability status represent disease categories that are preventable and treatable. For instance, diabetes and otitis media are two conditions disproportionately represented in certain Indian groups. In the general population, prevention and treatment of these conditions has been very successful, rarely resulting in permanent disabling conditions. However, in the Indian population, because of inaccessibility to services, noncompliance with medical regimens, cultural misunderstandings, and poor sanitation, these conditions often lead to permanent and severe disabilities.

In addition, many of the identified behavioral and environmental risk factors associated with the causes of excess deaths among American Indians can be controlled, such as death due to accidents. Interagency cooperative efforts in the areas of public information and education, which would subsequently lead to increased referrals for rehabilitation services, could greatly enhance the level of knowledge and understanding of American Indian people in regard to rehabilitation and disabilities.

RECOMMENDATION 5: INCREASE EFFORTS TO CONDUCT COOPERATIVE INTERAGENCY ACTIVITIES

- The Indian Health Service is a primary agency with a major presence in Indian communities, serving approximately two-thirds of the Indian population. IHS should serve as a main vehicle for distributing information about disabilities and rehabilitation services to the Indian people, as well as provide client referrals for vocational rehabilitation services.

- Public information and educational materials should be developed that are specifically designed for American Indian people, prepared for limited English speakers, with recognition of the cultural characteristics of the population. These materials should emphasize preventive aspects of those health, behavioral, and environmentally-related issues that contribute to the disparity in the disability status between American Indian people and the general population.

- RSA should educate IHS and BIA Social Service agencies about disabilities and the eligibility requirements for vocational rehabilitation services, thus increasing the number and appropriateness of American Indian referrals to State VR programs.

Disability Specific Issues

Certain kinds of health and educationally-related disability conditions are disproportionately represented in the American Indian population, accounting for much of the disparity in the disability status between American Indians and members from the dominant society. Alcoholism is a major contributor to death and disability among American Indians. American Indians are 3 times more likely to be hospitalized for alcohol dependency than individuals from the general population. Alcoholism also contributes significantly to deaths due to accidents. In addition, alcoholism among the pregnant American Indian women population results in a poorer infant health status at birth, with the likelihood of long-term developmental delays and retardation, as exhibited by Fetal Alcohol Syndrome and Fetal Alcohol Effects, affecting a second generation of American Indians.

Sensory impairments, identified as conditions of the eye and ear, are also disproportionately represented in the IHS hospitalization data when compared to the U.S. general population.

The hospitalization rate for diabetes mellitus likely to result in a disabling condition was 2.8 times greater for American Indians than the U.S. population. Other major health conditions influence the disability status of American Indians and result in a disproportionate representation of American Indians in hospitalization data.

American Indian school age children are more likely to be identified as learning disabled, speech impaired, and multi-handicapped than children from other minority groups or Whites. However, despite the many disease conditions within the American Indian population resulting in hospitalizations which are known to contribute to mental retardation, e.g. hypertension complicating pregnancy, meningitis, and low birth weight, American Indians are less likely than the general U.S. population to be identified as mentally retarded within the school-age population. They are less likely to be identified as seriously emotionally disturbed than children from the general U.S. population, which is consistent with the low rate of hospitalizations for psychological disorders (other than alcohol dependency) reported for American Indians. However, the high incidence of alcoholism among hospitalized American Indian patients may mask or prevent diagnosis of other psychological disorders.

The information related to specific disability conditions which seem to be disproportionately represented within the American Indian population suggest the following recommendations.

RECOMMENDATION 6: INCREASE REHABILITATION EFFORTS FOR AMERICAN INDIANS DISPROPORTIONATELY REPRESENTED IN CERTAIN DISABILITY-RELATED CONDITIONS

- The State-Federal rehabilitation system should evaluate its policies and practices related to alcohol dependency as a disability. Determination of VR eligibility and treatment services for individuals with alcohol dependency varies greatly by State and results in uneven service patterns to this disability group. Counselors should be provided with incentives to rehabilitate the American Indian with alcohol dependencies in order to address the critical needs of a large percentage of American Indians with this type of disability.

- State VR agencies should increase cooperation with other alcohol treatment programs and mental health facilities serving American Indians in order to conduct prevention campaigns and decrease the number of individuals disabled by alcoholism dependency.

- IHS should continue to implement pediatric registries nation-wide with a national standardized reporting scheme, in order to document conditions likely to be disabling or known to be disabling from birth through young adulthood. This would enable American Indian children to be identified as early as possible and early intervention programs for children with handicapping conditions could be implemented.

- State VR agencies should initiate efforts to increase services to American Indians who are mentally retarded and further determine the nature and extent of mental retardation among American Indians.

- State VR agencies should initiate efforts to increase the identification of American Indians with sensory impairments and improve services to this group, which is currently underrepresented in the RSA client caseload. This could be done through cooperative efforts with IHS.

- RSA should increase its efforts to work cooperatively with IHS, BIA, tribal governments, and other appropriate service agencies in order to assess the source and cause of accidents and injuries resulting in physical disabilities among American Indians. Educational safety and prevention campaigns could then be conducted.

Employment Factors Influencing Rehabilitation

Competitive employment is a major goal of vocational rehabilitation. The historically high unemployment rate of American Indians creates a major barrier to successful vocational rehabilitation. Unemployment affects the economic status of individuals and families. With decreased financial resources, an individual may be consumed with meeting the basic needs for subsistence living which may detract from pursuing his/her fullest vocational potential. Given the expanse of many Indian reservations, decreased financial resources may prevent a potential American Indian VR client from traveling to available rehabilitation services.

Additionally, American Indian occupational patterns and distribution of the type of disabling conditions most prevalent in the population suggest that there is a negative interaction between the nature of the disabling condition and the continued employment in preferred and available occupational categories. That is, American Indians are more likely to be employed in service and operator/fabricator/laborer occupations, which tend to require physical activity. However, the high incidence of disability in the sensory impairments, orthopedic conditions due to accidents, and alcoholism categories suggest disabling conditions that may prevent continued employment in the occupational patterns most prevalent among American Indians.

Evidence from the unemployment and occupational patterns analysis suggest the following recommendation:

RECOMMENDATION 7: INCREASE THE EMPLOYMENT STATUS OF AMERICAN INDIANS WHO ARE DISABLED

- Given the employment history of American Indian people and their lack of exposure to occupational opportunities, rehabilitation policy-makers and service providers should facilitate the development of jobs for American Indian people with disabilities within the existing job market, particularly on and adjacent to reservations.

- Efforts should be made to inform employers about the benefits of hiring persons with disabilities and employment incentives such as on-the-job-training programs and targeted tax credits.

- State VR agencies should cooperate with tribal agencies, such as departments of labor, health, education, and other tribal programs, such as JTPA, to develop jobs in the existing labor market for American Indians who are disabled. Self employment through cottage industries, vending businesses, crafts production, and opportunities in other industries should be explored.

- Rehabilitation counselors and evaluators should utilize culturally sensitive vocational assessment instruments when determining the vocational interests and potential of American Indians who are disabled.

- Rehabilitation counselors should increase efforts with American Indian VR clients to expose them to the world of work and provide information on occupational opportunities to which they may not previously have been exposed.

- State VR agencies should increase cooperation with school systems and Departments of Labor to develop summer job training programs and other youth employment opportunities to expose American Indian children who are disabled to the world of work and develop positive work histories.

- With a lack of industrial employment opportunities on reservations, relocation of American Indians for vocational training and employment will continue to be a necessity. Rehabilitation counselors should establish culturally sensitive off-reservation support networks to insure the successful transition of American Indian clients. Systematic follow-along services should be provided.

- Efforts should be made to provide independent living and physical/mental restoration services to American Indians with severe disabilities who may have restricted vocational potentials.

Data Limitations and Development

Although data currently collected by the major agencies who constituted the sources of information analyzed in this report are useful, limitations of the data are numerous and have been described within each of the individual study reports. One notable problem is the lack of uniformity across data sources in the method and recording of ethnicity identifiers. Few state data sources systematically record American Indian ethnicity. Although the Office of Management and Budget (OMB) provides minimum requirements for the recording of race and ethnicity in Federal data collection efforts, many statistical files and databases fall short of meeting the OMB minimum requirement (U.S. Department of Health and Human Services, 1985). In light of the need to improve the collection of meaningful data related to American Indians who are disabled, the following recommendation is made.

RECOMMENDATION 8: IMPROVE THE DATA AVAILABLE ON AMERICAN INDIANS WHO ARE DISABLED

- To the greatest extent possible, American Indians should be oversampled when conducting national surveys in order to allow for meaningful analysis related to their particular status on key issues.

- Standards for identifying and collecting information related to American Indian ethnicity should be encouraged at the federal and state level in order to facilitate further national and state level analyses.

Recommendations for Future Research

Analysis and synthesis of the data generated by this study has resulted in the identification of several major areas in need of future research in order to recommend solutions to improving rehabilitation services to American Indians who are disabled. They are as follows:

- An investigation of the nature and extent of existing services for American Indians with disabilities both on and off the reservation should be conducted in order to determine the gaps in services and identify available resources which could be coordinated in the effort to increase rehabilitation services.

- The nature of cooperative efforts currently conducted by State VR agencies with tribal organizations and other service agencies should be further investigated to determine the most effective strategies for developing rehabilitation services to American Indian people. Identification of the elements of the cooperative efforts that are most influential in contributing to successful relationships with tribal organizations and other agencies would assist those States in the development stage of implementing policies and activities related to Part D, Section 101(20) and Section 130 of the Rehabilitation Act.

- A further analysis of mental retardation as a disabling condition within the American Indian population should be undertaken. The issue is related to the fact that the socioeconomic status and disease-related conditions of the population place them at extreme risk for mental retardation. Since mental retardation alone may be insufficient reason for hospitalization, the IHS diagnostic hospitalization data may underrepresent this important disability group. The issue is complicated by the complexity of the diagnostic process for determining eligibility for bilingual, limited English speakers and the utilization of diagnostic instruments that are culturally biased and lack appropriate norming samples for American Indians. This may be an important reason for their underrepresentation in the school-based data. The discrepancy between indicators of mental retardation and reported prevalence is important enough to warrant further investigation.

- An analysis of the availability of indigenous personnel for delivering rehabilitation services to American Indian people should be conducted. This survey would assess the current educational levels and expertise of American Indians in Indian communities who work in the human services field, and identify the training needs of these individuals as they relate to serving individuals with disabilities in a variety of paraprofessional and professional positions.

- Further analysis related to the incidence of alcoholism should be conducted to determine whether or not American Indians entering IHS hospitals and diagnosed as exhibiting a primary condition of alcohol dependency have hidden, underlying psychological conditions which may go untreated but are contributing to the problem of alcohol dependency. Diagnostic issues related to the psychological assessment of American Indians would need to be addressed.

- A survey of employment opportunities at the local Indian community level should be conducted in order to determine the occupational opportunities on and near reservations, nature of self-employed businesses, and the experiences and attitudes of employers in hiring individuals with disabilities.

- An assessment of the needs of reservation Indians within the context of local communities should be conducted to identify the types of disabilities at the local, reservation level, and describe the functional needs of Indian people with disabilities in order to become successfully integrated into the reservation communities.

- Training models to teach adolescent American Indian students with disabilities about the world of work, with the establishment of career experiences should be undertaken.

- Research should be conducted to improve the methods of identifying handicapping conditions such as learning disabilities and mental retardation among American Indians who speak English as a second language.

- An investigation of the status of urban Indians in major urban centers should be conducted in order to determine how their employment, access to rehabilitation services, integration into the existing service systems, and cultural influences differ from those of reservation Indians.

- The development and evaluation of models for insuring the successful transition of rural, reservation-based American Indians with disabilities to urban areas should be undertaken.

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